



General Assembly

February Session, 2004

***Raised Bill No. 5201***

LCO No. 1014

\* \_\_\_\_\_HB05201APP\_\_041404\_\_\_\_\_\*

Referred to Committee on Insurance and Real Estate

Introduced by:  
(INS)

***AN ACT CONCERNING NEWBORN SCREENING AND MEDICALLY  
NECESSARY NUTRITIONAL FORMULA FOR CYSTIC FIBROSIS.***

Be it enacted by the Senate and House of Representatives in General  
Assembly convened:

1 Section 1. Section 38a-492c of the general statutes is repealed and the  
2 following is substituted in lieu thereof (*Effective October 1, 2004*):

3 (a) For purposes of this section:

4 (1) "Inherited metabolic disease" means a disease for which  
5 newborn screening is required under section 19a-55, as amended by  
6 this act.

7 (2) "Low protein modified food product" means a product  
8 formulated to have less than one gram of protein per serving and  
9 intended for the dietary treatment of an inherited metabolic disease  
10 under the direction of a physician.

11 (3) "Amino acid modified preparation" means a product intended  
12 for the dietary treatment of an inherited metabolic disease under the  
13 direction of a physician.

14 (4) "Specialized formula" means a nutritional formula for children  
15 up to age three that is exempt from the general requirements for  
16 nutritional labeling under the statutory and regulatory guidelines of  
17 the federal Food and Drug Administration and is intended for use  
18 solely under medical supervision in the dietary management of  
19 specific diseases.

20 (b) Each individual health insurance policy providing coverage of  
21 the type specified in subdivisions (1), (2), (4), (6), (11) and (12) of  
22 section 38a-469 delivered, issued for delivery or renewed in this state  
23 on or after October 1, 1997, shall provide coverage for amino acid  
24 modified preparations and low protein modified food products for the  
25 treatment of inherited metabolic diseases if the amino acid modified  
26 preparations or low protein modified food products are prescribed for  
27 the therapeutic treatment of inherited metabolic diseases and are  
28 administered under the direction of a physician.

29 (c) Each individual health insurance policy providing coverage of  
30 the type specified in subdivisions (1), (2), (4), (6), (11) and (12) of  
31 section 38a-469 delivered, issued for delivery or renewed in this state  
32 on or after October 1, 2001, shall provide coverage for specialized  
33 formulas when such specialized formulas are medically necessary for  
34 the treatment of a disease or condition and are administered under the  
35 direction of a physician.

36 (d) Such policy shall provide coverage for such food products and  
37 formulas on the same basis as outpatient prescription drugs.

38 Sec. 2. Section 38a-518c of the general statutes is repealed and the  
39 following is substituted in lieu thereof (*Effective October 1, 2004*):

40 (a) For purposes of this section:

41 (1) "Inherited metabolic disease" means a disease for which  
42 newborn screening is required under section 19a-55, as amended by  
43 this act.

44       (2) "Low protein modified food product" means a product  
45       formulated to have less than one gram of protein per serving and  
46       intended for the dietary treatment of an inherited metabolic disease  
47       under the direction of a physician.

48       (3) "Amino acid modified preparation" means a product intended  
49       for the dietary treatment of an inherited metabolic disease under the  
50       direction of a physician.

51       (4) "Specialized formula" means a nutritional formula for children  
52       up to age three that is exempt from the general requirements for  
53       nutritional labeling under the statutory and regulatory guidelines of  
54       the federal Food and Drug Administration and is intended for use  
55       solely under medical supervision in the dietary management of  
56       specific diseases.

57       (b) Each group health insurance policy providing coverage of the  
58       type specified in subdivisions (1), (2), (4), (6), (11) and (12) of section  
59       38a-469 delivered, issued for delivery or renewed in this state on or  
60       after October 1, 1997, shall provide coverage for amino acid modified  
61       preparations and low protein modified food products for the treatment  
62       of inherited metabolic diseases if the amino acid modified preparations  
63       or low protein modified food products are prescribed for the  
64       therapeutic treatment of inherited metabolic diseases and are  
65       administered under the direction of a physician.

66       (c) Each group health insurance policy providing coverage of the  
67       type specified in subdivisions (1), (2), (4), (6), (11) and (12) of section  
68       38a-469 delivered, issued for delivery or renewed in this state on or  
69       after October 1, 2001, shall provide coverage for specialized formulas  
70       when such specialized formulas are medically necessary for the  
71       treatment of a disease or condition and are administered under the  
72       direction of a physician.

73       (d) Such policy shall provide coverage for such food products and  
74       formulas on the same basis as outpatient prescription drugs.

75       Sec. 3. Section 19a-55 of the general statutes, as amended by section  
76       5 of public act 03-3 of the June 30 special session, is repealed and the  
77       following is substituted in lieu thereof (*Effective October 1, 2004*):

78       (a) The administrative officer or other person in charge of each  
79       institution caring for newborn infants shall cause to have administered  
80       to every such infant in its care an HIV-related test, as defined in section  
81       19a-581, a test for phenylketonuria and other metabolic diseases, cystic  
82       fibrosis, hypothyroidism, galactosemia, sickle cell disease, maple syrup  
83       urine disease, homocystinuria, biotinidase deficiency, congenital  
84       adrenal hyperplasia and such other tests for inborn errors of  
85       metabolism as shall be prescribed by the Department of Public Health.  
86       The tests shall be administered as soon after birth as is medically  
87       appropriate. If the mother has had an HIV-related test pursuant to  
88       section 19a-90 or 19a-593, the person responsible for testing under this  
89       section may omit an HIV-related test. The Commissioner of Public  
90       Health shall (1) administer the newborn screening program, (2) direct  
91       persons identified through the screening program to appropriate  
92       specialty centers for treatments, consistent with any applicable  
93       confidentiality requirements, and (3) set the fees to be charged to  
94       institutions to cover all expenses of the comprehensive screening  
95       program including testing, tracking and treatment. The fees to be  
96       charged pursuant to subdivision (3) of this section shall be set at a  
97       minimum of twenty-eight dollars. The commissioner shall adopt  
98       regulations, in accordance with chapter 54, specifying the abnormal  
99       conditions to be tested for and the manner of recording and reporting  
100       results. On or before January 1, 2004, such regulations shall include  
101       requirements for testing for amino acid disorders, organic acid  
102       disorders and fatty acid oxidation disorders, including, but not limited  
103       to, long-chain 3-hydroxyacyl CoA dehydrogenase (L-CHAD) and  
104       medium-chain acyl-CoA dehydrogenase (MCAD).

105       (b) The provisions of this section shall not apply to any infant whose  
106       parents object to the test or treatment as being in conflict with their  
107       religious tenets and practice.

This act shall take effect as follows:	
Section 1	<i>October 1, 2004</i>
Sec. 2	<i>October 1, 2004</i>
Sec. 3	<i>October 1, 2004</i>

***INS***      *Joint Favorable*

***PH***      *Joint Favorable*

***APP***      *Joint Favorable*